



President's Message

Greetings Illinois HD Families,

Happy Summer! Time is flying, and we are half-way through the year. Our Board has a lot planned for the families to help spread the awareness of Huntington's Disease still to come in the rest of the year.

Before I get started I would like to take a moment and congratulate an AMAZING couple that has put their heart and soul into the Illinois HDSA Chapter. Dave and Susie Hodgson have hosted our 1st Team Hope Walk for 15 years! In those **15 years** they have raised **1 million dollars** for HDSA! Congratulation and thank you for all your hard work and dedication to this organization and the families

of Illinois!

The NYA (National Youth Alliance) has a retreat planned in Chicago for the end of July. Youth can sign up at nya.hdsa.org. Our youth play an important role helping with the education of HD. The NYA is vital to our organization, and they are the future of our organization. I believe in their mission, of being the last generation with Huntington's Disease. Their fight is courageous, and this group puts it all out there to help make that mission possible. The energy that they have is a reminder that we have a lot to look forward to in our future, and that was exhibited at the recent HDSA Convention in Boston.

The National HDSA Convention was held at the end of June. I consider Convention a time to recharge. The energy of the NYA helped in that recharge reminder to remind me why I do what I do for this organization. Not only was it a time for recharging and seeing our HD Family members that we maybe only see once a year, but it is a time for HOPE! Convention was full of hope and research updates to inform us on how much closer scientist are to finding a cure! You can view some of the sessions that were recorded at the convention at hdsa.org.

Convention is also a time to be recognized for the efforts that we do at the local level for our efforts in following the mission of our organization: to improve the lives of everyone affected by Huntington's Disease and their families. In my three years of being on the Illinois HDSA Board I have been a part of the transformation and implementation of some new ways that we work together as a board. We have brought in new committees one being one that works with our three Centers of Excellence, and another works with our new board members. At Convention the Illinois Chapter was awarded the Outstanding Board Development Award. Charlotte Rybarczyk our Chapter Treasurer and National Field Committee Representative and myself accepted the award on behalf of our Chapter. Our Chapter was recognized for our efforts in creating a new system to help volunteers to join our board, and to help them learn the ins and outs of what we do. It is truly an honor to work with a great group of people that share the same passion. We are always looking to have more people join our Board. Why wouldn't you want to join an award-winning Chapter? If you are interested in joining us please do not hesitate to reach out to myself or any other AWESOME member, our contact information can be found in this newsletter.

I look forward to seeing you at one of our upcoming events! Please let me know if you have any questions at all.

See you soon,

Larry Haigh
President, HDSA Illinois Chapter

BECOME A VOLUNTEER - MAKE A DIFFERENCE





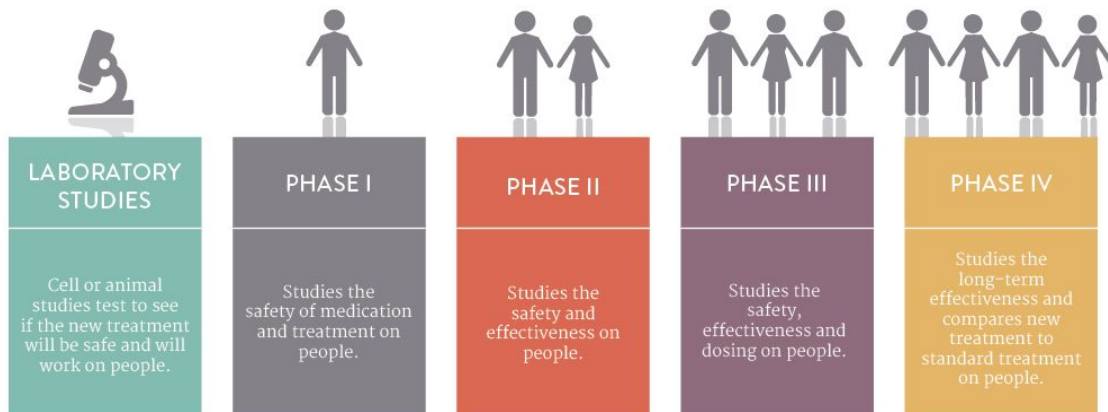
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RESEARCH 101

I have had many questions about research studies in the Huntington’s disease clinic. In this newsletter, I would like to tell you how a new therapy gets approval for use in the US. Approval for a new medicine or surgical therapy for Huntington’s disease will go through several phases before you are able to buy the medicine at a pharmacy.

Medication approval takes five phases of study before they are approved. The five phases are illustrated below.

- **Laboratory studies** – These studies test the medication to make sure it is safe to be used in humans. Most medicines are tested in animals before they are approved by the FDA for human testing.
- **Phase I studies** – In these studies, medicines are tested for the first time in a small group of people (20-80) who are healthy or have the disease. The purpose is to learn about the **safety** and **side effects** of the medicine.
- **Phase II studies** – The new medicine is then given to a larger group of people (100-300) to determine if it is **effective** for symptoms of the disease and to get more information on safety.
- **Phase III studies** – The new medicine is given to a much larger group of people (1000s) to **confirm it is effective and safe** to go on the market.
- **Phase IV studies** – This phase occurs after the FDA approves a medicine to look longer at the safety.



BrainsfortheCure.org

Studies in Huntington’s disease have typically required smaller numbers of volunteers because the disease is less common than diseases such as diabetes or high blood pressure. There are gene therapy studies being conducted by multiple pharmaceutical companies for Huntington’s disease in all 4 phases currently. Compound RO7234292 by Hoffman-La Roche is in Phase III and will be recruiting 660 participants around the world with an anticipated study completion date of August 1, 2022. At that time, we will know if the compound is safe and effective for use by all patients.

Observational studies are studies that observe Huntington’s patients over time and allow researchers to learn about how the disease changes and whether there are biomarkers that can show us evidence of this change. The largest observational study is Enroll-HD, a registry study that started in 2012, which follows 1000s of Huntington’s disease patients from 173 sites around the world. These types of studies will inform our design of clinical trials for medication approval.

This is an exciting time for us in Huntington’s disease. However, for us to have medicines that slow or halt progression of the disease, we need volunteers with and without the disease to enroll into all types of clinical studies. Help us to move the field forward by asking your neurologist about how you can enroll in a Huntington’s disease study.



HDSA IL Chapter Baggo Tournament

Double Elimination

When: Saturday, August 24, 2019 (rain date – August 25th)

Time: 1:00pm (Team Check in at 12:30pm)

Where: The Home of Charlotte Rybarczyk
3000 Owl Drive, Rolling Meadows, IL 60008



Registration Fee:

\$60/Team ~ \$15/Spectator
(Sponsorship Opportunities Available)



****Vienna Hot Dogs, Beef Sandwiches and Lemonade included****
Your donation is 100% tax deductible

Winning team receives \$100 plus each player chooses one of our custom Baggo sets!

Any questions, contact Charlotte Rybarczyk at 847-259-3593 or charlotte82963@gmail.com

**Return registration form and check made payable to HDSA IL Chapter by August 17th to:
HDSA IL Chapter, P.O. Box 1883, Arlington Heights, IL 60006**

TEAM NAME: _____

Player #1 Name: _____

Player #2 Name: _____

Phone Number: _____

Email Address: _____

Spectators: Name(s) _____ How many? _____

Baggo Tournament Sponsorship

The Huntington's Disease Society of America (HDSA) invites your company to become a local sponsor for the 3rd Annual Illinois Chapter Baggo Tournament being held on Saturday, August 24th, 2019, in Rolling Meadows, Illinois. Events such as this are a way to show how local communities of inspired individuals can join to make a difference.

Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. HD is known as the quintessential family disease because every child of a parent with HD has a 50/50 chance of carrying the faulty gene. Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease. Many describe the symptoms of HD as having ALS, Parkinson's and Alzheimer's – simultaneously.

A local sponsorship of the Illinois Baggo Tournament for **\$250.00 or more** is an excellent opportunity for your company to support a great cause and to take advantage of a wonderful marketing opportunity. As a local sponsor, your company will be increasing your brand recognition and visibility, demonstrating your commitment to the local community your employees and customers live and work in.

Proceeds from the Baggo Tournament support the mission and programs of HDSA, the largest voluntary health agency dedicated to finding a cure and providing assistance to those individuals living daily with HD. **Any donation at or above \$250** will qualify your company's logo to be placed on sponsor signage at the tournament and will include one team as well as food and beverages for the team.

YOUR DONATION IS 100% TAX DEDUCTIBLE!

COMPANY NAME: _____

Phone Number: _____

Email Address: _____

Team Name: _____

(one team participation included with sponsorship)

Player #1 Name: _____

Player #2 Name: _____

**PLEASE RETURN FORM WITH YOUR CHECK PAYABLE TO HDSA IL CHAPTER AND MAIL TO:
HDSA IL CHAPTER PO BOX 1883, ARLINGTON HEIGHTS, IL 60006-1883**

PO Box 1883, Arlington Heights, IL 60006 | T. 630 443-9876 | www.hdsa.org/il



HDSA meets all Standards of Excellence of the Better Business Bureau Wise Giving Alliance, National Health Council and the American Institute of Philanthropy



Federal employee?
Support HDSA through the Combined Federal Campaign
Designate #0526



BREAKING NEWS FROM THE 34TH ANNUAL HDSA CONVENTION FROM UNIQUIRE

Our friends at uniQure are proud to announce that AMT-130 will be the first one-time administered gene therapy to enter clinical testing for the treatment of Huntington's disease. uniQure has a long history in developing gene therapies but is a relative newcomer to the HD community.

What is gene therapy? Genes within our cells provide a blueprint to produce proteins. Proteins are essential structural and functional components of all living organisms. DNA variations in genes can cause the blueprint to be wrong – this is the cause of many diseases. Gene therapy provides a way to correct a missing or defective protein, or to reduce the production of an abnormal disease-causing protein. The goal? A single treatment that is administered only once with long-term benefits.

The clinical trial uniQure is planning to conduct in HD uses a gene therapy known as AMT-130. This investigational treatment will be the first one-time administered gene therapy to enter clinical testing for the treatment of HD. AMT-130 is administered only once by neurosurgical procedure. There are two key components to AMT-130, a vector and a gene encoding a microRNA. The vector acts as a delivery system and is based on a non-disease causing adeno-associated virus (AAV) that has been changed to carry and deliver a gene encoding a microRNA that will recognize, bind and non-selectively lower the human huntingtin protein. microRNA (or miRNA) are small pieces of genetic material that can prevent production of a given protein. To “non-selectively lower” human huntingtin protein means that production of both the disease-causing mutant (mHTT) and normal huntingtin protein (HTT) will be decreased.

The objectives of the Phase I/II clinical trial are to assess the safety, tolerability and efficacy of AMT-130 in patients with HD using a dose-escalating, randomized, and double-blinded control design. uniQure expects to open several clinical sites in the United States and begin enrolling patients in the second half of 2019.

What is involved in the study?

It is important to reiterate that AMT-130 is administered only once. The study will test two dose levels of AMT-130 (low dose and high dose). The safety of the low dose will be assessed before testing the high dose. A total of 26 patients will be enrolled. Of the 26 patients enrolled, 16 will receive treatment with AMT-130 (“Treated Group”) and 10 will not receive any study treatment (“Imitation Group”). Patients assigned to the Treated Group will receive the dose of AMT-130 during a neurosurgical visit. AMT-130 will be infused into two specific brain regions (caudate and striatum) under general anesthesia. This is done by drilling two to six small holes in the skull and administering AMT-130 by a micro-catheter. For patients assigned to the Imitation Group, small, superficial holes will be drilled into the surface of the skull under general anesthesia, but they will NOT receive a dose of AMT-130. The main part of the study lasts for 18 months, with additional annual visits out to 5 years for continued safety follow up. Procedures will include clinic visits, assessments of physical and neurological health, a neurosurgical procedure, lumbar punctures (LP), brain scans, and samples from body fluids. The study is “double blinded” meaning neither the patient, the investigator or clinical staff will know if the patient is in the Treated Group or the Imitation Group.

Who is eligible for the study?

The inclusion criteria include, but are not limited to:

- Patients with a definitive clinical diagnosis of early manifest HD
- Genotype of 44 CAG repeats or greater in the huntingtin gene
- Between the ages of 25 to 65 years old

What are the next steps for the trial?

The uniQure HD team is working as quickly as possible to get sites ready for screening patients for eligibility. We hope to enroll the first patients in the second half of 2019. We will continue to work with the team at HDSA to communicate important information to the community when appropriate. In the meantime, thank you for your interest in our program. The entire uniQure HD team look forward to working with the community to make progress in developing a treatment for Huntington's disease.

READ FULL COMMUNITY STATEMENT FROM UNIQUIRE AT HDSA.ORG

SAVE THE DATE

Continue to check the IL Chapter website
for additional details on future events:
<http://hdsa.org/il>



Golf Outing to benefit the HDSA IL Chapter
Saturday, July 13th (Village Greens of Woodridge)



HDSA IL Chapter Team Hope Walks
Sunday, September 8th (Galesburg, IL)
Sunday, September 15th (Bloomington, IL)



HDSA IL Chapter Education Symposium-Peoria, IL
Saturday, November 9th (watch HDSA IL chapter website for more information and registration info coming soon)

Rush Center of Excellence Half Day Symposium

Date: October 12, 2019

Location: Searle Conference Center, Rush Professional Building
1725 W. Harrison St., Chicago, IL 60612

Time: 8:30 A.M – 12:30 P.M.

RSVP: by October 1, 2019

The free to attend event will include our featured guest speaker, **Dr. Kathleen Shannon**, updates on research, and a question and answer panel. For additional questions please call 312-563-3796 or email: movement_hd@rush.edu.

Veterans in Need of VA Neurologist Who Works with HD Patients

Already enrolled in the VA - request a consultation from your current physician to see Dr. Barton at the Jesse Brown VA. If they are not patients at Jesse Brown but are seen at another VA, they can get referred to Jesse Brown through an interfacility consult, which could be placed by any of their current VA doctors, preferably the PCP. This is done internally through the VA order system.

Not enrolled in the VA - apply for VA health care <https://www.va.gov/health-care/how-to-apply/>

Once enrolled in the VA healthcare system request a consultation to see Dr. Barton at the Jesse Brown VA. This is usually accomplished by establishing care with a PCP first, then requesting a referral to see Neurology for a consultation, with Dr. Barton's name listed specifically. Any specialist could refer to neurology, but sometimes the order is not approved unless seen by a PCP first. This is done internally through the VA order system.

Stroger Hospital of Cook County – Dr. Bailey treats HD patients, make appointment with the neurology clinic staff at 312-864-2971 to see him.



Fresh Updates from First Huntingtin Lowering Study Publication

Hot off the presses – New publication gives more details about the results of Ionis and Roche's safety study with a Huntingtin-lowering ASO
By Dr Jeff Carroll May 07, 2019 Edited by Dr Tamara Maiuri

Today saw the publication of the first manuscript describing a huntingtin lowering trial in Huntington's disease patients. This study, sponsored by Ionis and Roche, provided clear evidence of researchers' ability to safely reduce mutant huntingtin protein in the spinal fluid. An overview of these results has previously been shared, but this manuscript provides important new information about the results of this remarkable trial. What'd we learn?

Huntingtin lowering: a little background

Huntington's disease (HD) is caused by a single mutation in a gene we refer to as the HD gene. Like most genes, the HD gene is used by cells as instructions to create a little cellular machine called a protein, which we call **huntingtin**. The genetic mutation that causes HD also changes this protein, which we refer to as **mutant huntingtin**.

While HD symptoms are complex, it has simple genetics - if you inherit a single mutant copy of the HD gene from either your mother or father, you will develop HD. Since we know that one must inherit a mutant HD gene to develop HD symptoms, could we interfere with the process of making the mutant huntingtin protein? If so, would that slow or prevent the progression of Huntington's disease?

That general approach, which we refer to as **huntingtin lowering** has been a major focus of HD researchers for several years, and several companies are pursuing this target. Two companies - Ionis and Roche Pharma - are running the most advanced program, in collaboration with several academic researchers around the world led by Prof. Sarah Tabrizi, University College London.

Excitingly, today saw the release of the first official manuscript describing these huntingtin lowering efforts in HD patients, and it provides new information about the first trial. This trial was focused on understanding whether treatment with a huntingtin lowering drug called an antisense oligonucleotide or **ASO** is safe.

Endpoints, Endpoints, Endpoints

As in any clinical trial, this study included a number of *endpoints*. Endpoints are just the target, or goal, that you want your study to accomplish. In future HD trials, this might include things like improved movement or thinking. But for a new drug that has never been tested in people, the endpoint is always safety, safety, safety.

Formally, researchers say that safety is the primary endpoint of the study. This just means it's the sole criteria we'll use to judge whether the trial is a success or failure. If the drug turns out to be unsafe, the trial fails. If there are no safety concerns, the study is a success.

While we'd obviously like be able to tell whether a drug is safe *and* whether it helps HD symptoms at the same time, we can't achieve both goals in the course of a single study. This is because it takes large numbers of participants - many hundreds - to tell whether a drug is influencing HD symptoms. But for a safety study, we want to treat the smallest reasonable number of people to reduce the number of people exposed to the risk of testing a drug for the first time.

While trials usually have one primary endpoint, researchers are curious about other possible impacts of their drug on HD-related changes. These other measurements are called secondary endpoints - this term helps us remember that the main, or primary, goal of the trial is to determine safety, but we have many secondary measurements we're interested in examining.

This study included a large number of secondary endpoints, focused on participants' HD symptoms, brain scans and lab tests to measure specific markers in the blood and spinal fluid. The new manuscript is exciting, because it's the first chance

we've had to look at the raw data produced in the study. The interesting results of some secondary endpoints are discussed below, but it's important to remember that determining safety was the primary goal of everyone working on this trial.

No Serious Adverse Event

"Since we know that one has to inherit a mutant HD gene to develop HD symptoms, could we interfere with the process of making the mutant huntingtin protein? If so, would that slow or prevent the progression of Huntington's disease?"

The data published in this new paper generally supports the safety of the drug, called Htt-Rx, in HD patients. The most important safety outcome measure is a list of what researchers call **adverse events**. These can be anything that causes distress to people, running the gamut from mild (a headache that resolves in a few days without treatment) to severe (a heart attack or suicide attempt).

Of course, in any group of dozens of people followed closely for several months, there's bound to be some adverse events. This is why having a **placebo**, or dummy treatment, group is so important in studies like this. By comparing the rate at which people in the trial experience adverse events, we can measure whether they occur more frequently in people given real drug, as opposed to the placebo injections. There were no severe adverse reactions in any of the groups in the trial. Excitingly, no participants withdrew from the study, suggesting folks in the trial felt able to handle the repeated spinal injections and many tests administered.

Mild adverse events did occur during the study, but people receiving placebo treatment were exactly as likely to experience them as people receiving the drug. This suggests that these effects are not due to the drug itself, but rather the procedure of spinal fluid injections, or just bad luck. The most common side effect was a post-treatment headache, which is known to occur sometimes after spinal fluid injections.

NfL Changes

This study used several newly developed tests that raise some potential safety concerns worthy of additional study. First, the team measured the levels of a marker called neurofilament light, or NfL, in the spinal fluid of people in the study. This marker is released by sick and damaged brain cells called neurons, and researchers have previously demonstrated that it increases slowly and predictably in HD mutation carriers. This study used several newly developed tests that raise some potential safety concerns worthy of additional study. First, the team measured the levels of a marker called neurofilament light, or NfL, in the spinal fluid of people in the study. This marker is released by sick and damaged brain cells called neurons, and researchers have previously demonstrated that it increases slowly and predictably in HD mutation carriers.

Surprisingly, in the patients receiving higher doses of ASO, there was a brief *increase* in the levels of NfL, suggesting some kind of stress on neurons after delivery of a high dose of drug. According to the data presented in the paper, this increase in NfL returned to normal during the course of the study, even though people continued to receive injections of the drug. The meaning of this isn't clear - researchers were measuring NfL in hopes of eventually seeing a *reduction* in its levels, not an increase. However, the increase was relatively small, and seems to have returned to normal.

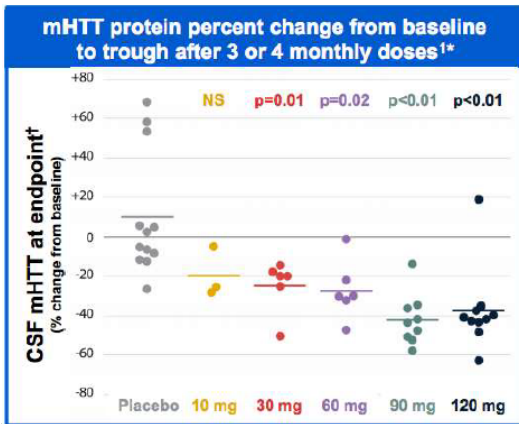
This increase in spinal fluid NfL is weird, frankly, and you can be sure that researchers at Roche are thinking about how to get to the bottom of it in the longer, on-going, studies with this drug. If there were any sign that this increase in NfL levels was associated with adverse impacts on brain function, we would know by now, so that doesn't seem to be the case.

Brain Imaging Changes

Another finding worthy of additional study arises from brain imaging called magnetic resonance imaging or MRI. This kind of brain scan uses giant magnets to take a picture of the shape of participants' brains. Many years of work by HD researchers have defined very precise changes in brain shape that occur as HD progresses. One of these changes is a progressive increase in the size of the brain's ventricles - the fluid filled spaces within the brain tissue. During the course of HD, these spaces appear to grow, as the tissue around them shrinks.

In the higher-dose groups, the volume of these fluid-filled spaces actually increased during the study, which is the opposite effect one would hope for if the drug was slowing brain shrinkage. This effect could be a real response to ASO treatment, or it could be due to unexpected physical changes in the brain thanks to some other aspect of delivering large doses of ASOs, and have nothing to do with HD.

As with the brief increases in NfL, the impact of these brain changes is not yet clear. What is clear is that these changes aren't associated with changes in brain function, at least as far as researchers can tell in this initial study.



This key graph from the paper describes the relationship between the dose of ASO given to patients, and the amount of Huntingtin in the spinal fluid

Getting to the bottom of these potentially concerning lab tests requires a larger group of people, followed for a longer time. This is exactly why Roche and Ionis are conducting a new, larger, study called the GENERATION-HD1 study.

Where do ASOs go?

Another major outcome from this study is a better understanding of how ASOs move around the body after being injected into the spinal fluid. Based on a large number of animal studies, Ionis and Roche built a computer program to predict how much ASOs would be found in the spinal fluid (and brain) after being injected into people.

Models like this are really important because they help researchers plan how much drug to inject, and how frequently they need to inject it to keep levels of the drug high enough to do its job. In the study of HTT-Rx, researchers measured how much ASO was in the spinal fluid (and blood, where it shows up as it's being cleared away).

These results proved that the computer program was accurate at predicting how much ASO sticks around in the spinal fluid. This gives us confidence that the amount of ASO being injected, and the frequency at which it's being injected, are based on good assumptions. This will reduce the amount of guesswork involved in planning the next trials with this drug.

mHTT Knockdown

The overall goal of all this work is to reduce levels of mutant huntingtin in the brain. Unfortunately, for now, there's no direct way to measure mutant huntingtin in the brains of living patients. Brain tissue is irreplaceable, so we can't sample it to determine how much mutant huntingtin is there.

Luckily, we can guess at this by measuring levels of mutant huntingtin in the spinal fluid. This clear liquid bathes the brain, circulating and coming into contact with our entire brain throughout the course of a day.

For reasons that are still a little bit unclear, a tiny amount of mutant huntingtin is present in the spinal fluid of HD patients. Our current best guess is that this mutant huntingtin comes from the brain itself, rather than some other source. So, researchers have developed very sensitive tests for measuring mutant huntingtin levels in spinal fluid, to give a clue about the levels of mutant huntingtin in the brain.

Treatment with ASOs resulted in very clear reductions in levels of mutant huntingtin in the spinal fluid. While it's not direct proof of lowering huntingtin in the brain, it's the best evidence we could hope for to suggest that the drug has successfully lowered huntingtin levels.

"Treatment with ASOs resulted in very clear reductions in levels of mutant huntingtin in the spinal fluid."

What about HD symptoms?

Finally, investigators examined the relationship between treatment with Htt-Rx and HD symptoms. Remember, the duration and number of people in this study is intentionally low, to minimize the risk associated with testing a drug in people for the first time. That means there's not enough people in the study - and they weren't followed long enough - to be definitive about any changes seen in symptoms. And, indeed, there is no large difference in the HD symptoms measured in participants during this short study.

Thanks to newly developed lab tests for measuring mutant huntingtin in the spinal fluid, we have a sense of how much mutant huntingtin lowering is occurring in each patient. As an early exploration of their data, the researchers examined the relationship between how much mutant huntingtin was lowered in the spinal fluid of each participant, and the severity of their HD symptoms.

There are some intriguing correlations observed - notably, people with the greatest reduction in mutant huntingtin tended to also have better symptoms. The researchers appropriately point out that these results should be taken with a grain of salt until we look in a bigger group of people for a longer time, but it's very exciting that larger reductions of mutant huntingtin are correlated with better HD symptoms.

Take Home Message

The study described in this new manuscript represents a huge investment of time, effort and hope by everyone involved. The 46 volunteers and their families deserve enormous gratitude from the HD community, as they took on some risk in testing a drug with the potential to address HD's underlying cause. Physicians and researchers in academic labs, at Roche and especially at Ionis also deserve enormous credit for developing these drugs and bringing them to patients for testing.

What did we learn as a result of all this hard work? First - that lowering mutant huntingtin in the nervous system of HD patients is possible. This represents the first time we've been able to lower levels of the protein that causes HD in a targeted way. Second, we learned an enormous amount about how ASOs work in the body - how long they stick around in the spinal fluid and blood, which helps design future studies with more targeted delivery of drugs.

The primary endpoint of the trial, to determine whether this drug is safe, was met. There were no severe adverse events associated with this ASO being delivered to the spinal fluid of HD patients. There were some lab tests - including NfL and brain ventricle size - that do raise some concerns that need to be addressed in future studies. Luckily, these lab test results weren't associated with changes in brain function that we can measure.

In short, the now published results of the first study with a drug targeting the root cause of HD are a big leap forward for the community. They point towards refinements and cautions we should consider as we test the drug in larger groups of HD patients over a longer time. In fact, the next studies with this drug are already underway, suggesting everyone involved is working towards the goal of determining as quickly as possible whether these drugs are both safe and effective against HD.

15th Annual Team Hope Walk Recap

By Dave Hodgson, HDSA IL Chapter Vice President

This year's 15th Annual Team Hope Walk, held along the beautiful Riverwalk in downtown Naperville was a huge success! From balloon twisters to Skates, the Chicago Wolves Hockey team mascot, to the carnival bag raffle, 540 participants enjoyed a break in the rain to advocate for Huntington's Disease and support the mission of HDSA.

Louise Vetter, CEO of HDSA, thanked all those that showed up and helped us cut the ribbon. Thank you to Steiner Electric, TEVA NeuroScience, and Genentech for their major sponsorship of our Walk. To see the full list of sponsors, go to <https://illinois.hdsa.org/sponsors>. Preliminary figures show donations in excess of \$97,000 for this year's walk, allowing the HD families of Illinois to surpass the \$1,000,000.00 mark in total donations for 15 years of walking! Mark your calendar for next year's 16th Annual Team Hope Walk: May 17, 2020. We hope to see you there!





News from Our Illinois Chapter

Social Worker

Emily Zivin, LCSW

Huntington's Disease Society of America
Tel: 630-443-9876 or E-mail: ezivin@hdsa.org

Preparing for the future is something that all adults must do. For Huntington's Disease families, difficult conversations need to be had very early on. There are key legal documents and court procedures that need to be considered when planning for the future. Some of the important documents/procedures include:

Power of Attorney for Health Care: This document designates someone to be the representative agent, in the event that you are unable to make/communicate decisions in all aspects of your health care.

Power of Attorney for Property: This a legal document transferring the legal right to a person/agent to manage and access your property in the event that you are unable to do so for yourself.

Mental Health Declaration Form: This document allows an individual to make decisions in advance about three types of mental health treatment: psychotropic medication, electroconvulsive therapy, and short-term admission to a treatment facility. The instructions that are included in this declaration will be followed only if two physicians or a judge believes that an individual is incapable of making treatment decisions. Without a signature from two physicians or a judge, one will be considered capable to give or withhold consent for treatments. This document remains in effect for a period of three years unless the individual becomes incapable of participating in mental health treatment decisions. If this occurs, the directive will continue in effect until the individual is no longer incapable.

DNR stands for "do not resuscitate." A DNR order instructs medical personnel not to use cardiopulmonary resuscitation (CPR), electric shock to the heart, artificial breathing devices or other invasive procedures on you should you stop breathing or your heart stops beating.

Living Will. A living will is a directive for your medical care. This document lets individuals state their wishes for end-of-life medical care, in case they become unable to communicate their decisions. It has no power after death.

Special Needs Trust: A special needs trust, is also known as a supplemental needs trust. It is a specialized trust that allows the disabled beneficiary to enjoy the use of property that is held in the trust for his or her benefit, while at the same time allowing the beneficiary to receive essential needs-based government benefits.

Guardianship: Guardianship is a legal tool that allows one person or entity to make decisions for another. Individual cases are brought to the courts with the intent of establishing guardianship and they typically appoint guardians in instances of incapacity or disability.

****Please note, this is a simplified description of key legal documents. Please consult an attorney or financial planner for further and more detailed information.**

Memorials and Tributes

In Memory of Jared Gaymon from Nancy & Dennis Gaymon, Beverly Schmidt

In Memory of Ralph Short from Lois Short

In Memory of Dale & Dan Jackowski and Cheri Hinde from Gregory & Mary Linder

In Memory of Clarence Wiese from Alli & Eric Nietering, Tim & Virginia McClellan

In Honor of Bob Leck from Randy & Glory McCown

In Honor of Cheryl Hinde from William Hinde

In Honor of Steve Howard from Phil Morales

In Honor of Teresa Srajer on her birthday from Catherine and Richard Evers

Congratulations to our AMAZING HDSA Illinois Chapter Board! We were honored at the Annual HDSA Convention in Boston for *Outstanding Board Development!* This award is for all of you! It takes a village to do what we do and our village is AWESOME!!

Thank you as always for what you all do!
Keep up the amazing work!

-Larry Haigh, IL Chapter President



Larry Haigh and Charlotte Rybarczyk

Next Year's Convention in New Orleans



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Hopes & Dreams
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This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Illinois Chapter.



SUPPORT groups



****Whether you have HD, are at-risk, a caregiver, friend or just someone who wants to know more about HD, you are welcome!****

CENTRAL ILLINOIS

2nd Sunday of Even Months (2:30 – 4:30pm)

2019 Meetings: 2/10, 4/14, 6/9, 8/11, 10/13 (no Dec. meeting)

OSF PromptCare Fort Jesse, 2200 Fort Jesse Road, Normal, IL
Contact: Larry Haigh (815-383-1877); larryhaigh@gmail.com

MUNSTER, IN

2nd Tuesday of Even Months (7:00 – 8:30pm)

2019 Meetings: 2/13, 4/10, 6/12, 8/14, 10/9, 12/11

Southside Christian Church, 1000 Broadmoor Avenue
Contact: Cindy Rogers (219-836-2369); clogers111@comcast.net

ROCKFORD

2nd Sunday of Every Month (2:00 – 4:00pm)

OSF St. Anthony Medical Center, 5666 E. State Street,
St. Anthony Room (Use main entrance – second one back from
parking lot entrance. As you enter building, you'll see a counter
staffed by volunteers. Turn right, before you reach the counter.
St. Anthony room is straight ahead)

Contact: Dave or Susie Hodgson (630-386-3928);
dchodgson1946@gmail.com

CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL

Saturdays (see dates below) (10:00 – 11:30am)

2019 Meetings: 1/26, 3/16, 5/18, 7/20, 9/7, November group will
take place downtown right after HD Family Symposium

Logan Square Library, 3030 W. Fullerton Avenue, Conference
Room (Free ground-level parking available; building is
handicap-accessible)

Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org
Northwestern Social Worker: Danielle Marino;
danielle.marino@northwestern.edu

GENEVA

3rd or 4th Sunday of Odd Months (2:00 – 3:30pm)

2019 Meetings: 1/20, 3/24, 5/26, 7/21, 9/15, 11/17

Northwestern Medicine – Delnor Hospital, 300 Randall Road
Conf. Room #4, Medical Office Building 351 (park near the south
entrance to the hospital and enter at the southeast corner of the
building. Turn left, go past the gift shop and cafeteria, then
follow the sign for Building 351. Conference Room #4 is a short
ways down the hall on the right)

Contact: Joe Wiedemann (847-505-3933);
joseph.wiedemann@gmail.com

CHICAGO – RUSH UNIVERSITY MEDICAL CENTER

4th Tuesday of Even Months (7:00 – 8:30pm)

2019 Meetings: 2/26, 4/23, 6/25, 8/27, 10/22

Rush University Medical Center, 1620 W. Harrison Street,
Tower Resource Center, 4th Floor, Suite 04527

(Parking is available at the Rush garage on the southeast corner
of Paulina and Harrison Streets. From the 4th floor, follow the
signs to the Tower. Valet parking is available in front of 1620 W.
Harrison. Parking at both venues will be validated in full)

Contact: Sarah Mitchell Chen, LSW (312-942-6445)

LAKE COUNTY

2nd Monday of Every Month (7:00 – 8:30pm)

Advocate Condell Medical Center, 801 Milwaukee Avenue,
West Tower, Libertyville, IL

Contact: Marilyn & Barry Kahn (847-975-2403);
marilynkahn1@gmail.com
(Call for additional information and directions)

SOUTH SUBURBAN

2nd Tuesday of Odd Months (7:00 – 8:30pm)

2019 Meetings: 1/8, 3/12, 5/14, 7/9, 9/10, 11/12

Thomas Cellini Huntington's Foundation, 3019 East End Ave.
South Chicago Heights, IL

Contact: Maryann Moynihan (708-955-3080);
shamrock1959@att.net OR TCHF Office (877-687-8243)



Caregiver Support Group

Wednesdays (see dates below) (7:00 – 8:30pm)

2019 Meetings: 6/19, 8/21, 10/16, 12/4

Winnetka Library, 768 Oak Street, Winnetka, IL; Community Room

Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org

 SAVE THIS DATE!

July 13, 2019	Golf Outing benefiting the HDSA IL Chapter – Woodridge, IL
August 24, 2019	HDSA IL Chapter Baggo Tournament – Rolling Meadows, IL
September 8, 2019	HDSA IL Chapter Walk – Galesburg, IL
September 15, 2019	HDSA IL Chapter Walk – Bloomington, IL
November 9, 2019	HDSA IL Chapter Education Symposium – Peoria, IL

<https://hdsa.org/il>



SUMMER 2019